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OFFICE OF THE
SECRETARY

MURIEL BOWSER
MAYOR

NOV 1 2018

The Honorable Phil Mendelson
Chairman
Council of the District of Columbia
John A. Wilson Building
1350 Pennsylvania Avenue, N.W., Suite 504
Washington, D.C. 20004

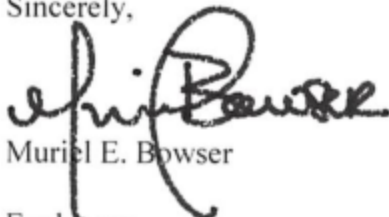
Dear Chairman Mendelson:

Pursuant to D.C. Law 17-249, I am transmitting the "Annual Report for Fiscal Year 2018 and Plan for Fiscal Year 2019 of the Department on Disability Services to the Council of the District of Columbia on Substitute Decision Makers and Psychotropic Medication Review for People with Developmental Disabilities." This report provides an aggregate analysis of the activities of the Department on Disability Services (DDS) related to identifying and securing substitute decision-makers for people supported by the Developmental Disabilities Administration (DDA) during Fiscal Year (FY) 2018 and presents the agency's plan for FY 2019.

This submission identifies established action steps to promote the availability of decision-makers and efforts to maintain an efficient system to ensure that every person receiving supports and services from the DDA has explored the least restrictive options for decision-making support as needed. The steps presented in the annual report and plan include an ongoing comprehensive review of substitute consent information for all individuals served by the DDA, initiatives with the Superior Court's Probate Division to ensure that court-appointed guardians have more access to information and education about individuals supported by the DDA, and community initiatives to educate the substitute decision-makers, health care entities, and provider communities about both supported decision-making and substitute decision-making, particularly revolving around person-centered thinking.

If you have any questions, please contact Andrew P. Reese, Director of the Department on Disability Services, at (202) 442-8663.

Sincerely,



Muriel E. Bowser

Enclosure



GOVERNMENT OF THE DISTRICT OF COLUMBIA
DEPARTMENT ON DISABILITY SERVICES
DEVELOPMENTAL DISABILITIES ADMINISTRATION

ANNUAL REPORT FOR FISCAL YEAR 2018 AND PLAN FOR FISCAL YEAR 2019
TO THE COUNCIL OF THE DISTRICT OF COLUMBIA
ON SUBSTITUTE DECISION-MAKERS AND PSYCHOTROPIC MEDICATION
FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

In accordance with D.C. Law 17-249, the “Health-Care Decisions for Persons with Developmental Disabilities Amendment Act of 2008,” D.C. Official Code § 7-1305.07a(b) and (d) (2013 Repl. and 2017 Supp.), the Department on Disability Services (DDS) hereby submits to the Council of the District of Columbia (Council) its Annual Report for Fiscal Year 2018 and Plan for Fiscal Year 2019 on Substitute Decision-Makers and Psychotropic Medication for People with Developmental Disabilities. This submission provides the DDS’s plan for complying with the policy mandates in D.C. Official Code § 7-1305.07a(a) (2013 Repl. and 2017 Supp.) in Fiscal Year (FY) 2019, and a review of the efforts made over the last fiscal year toward identifying and obtaining appropriate decision-making assistance as needed for people served by the Developmental Disabilities Administration (DDA).¹ The DDA encourages independent and supported decision-making whenever possible, the use of lesser restrictive types of decision-making supports whenever possible, and, as a last resort, works to obtain the appointment of legal guardians to serve as substitute health-care decision-makers when needed. In addition, this submission discusses the DDA’s tracking of prescribed psychotropic medications for people receiving services.

ANNUAL REPORT FOR FY 2018

I. SUBSTITUTE DECISION-MAKING

A. General Aggregate Statistics

Since the summer of 2009, the DDS Office of the General Counsel (DDS OGC) has continually maintained the information for all of the people served by the DDA with regard to decision-making needs and supports.

¹ The various emergency and temporary versions of the health-care decision-maker legislation in effect during FYs 2007 and 2008 required the DDS to prepare and submit quarterly reports regarding substitute consent within 15 days of the end of a fiscal quarter. In FY 2008, the DDS prepared and submitted reports covering the three-quarter period from July 1, 2007 through March 31, 2008, the quarterly period from April 1, 2008 through July 15, 2008, and the quarterly period ending September 30, 2008. These previously submitted quarterly reports reviewed progress made towards identifying and obtaining guardians for people served by the DDA. D.C. Law 17-249 required similar quarterly reporting, which DDS submitted from October 2008 through October 2010. Although D.C. Law 17-249 required quarterly reporting only through October 15, 2010, annual plans and reporting continue to be required. The statistical information provided in this submission is drawn from the data collected during FY 2017 and provides comparison back to FY 2009. Note that the averages from quarterly reports may have been skewed by outliers, may have had small sample sizes at times, and did not have medians for accurate comparison.



To ensure that the most accurate information is collected, the DDS OGC's review involves cross-referencing court records from the D.C. Superior Court's Probate Division with: (1) information on the record with the D.C. Superior Court's Mental Health and Habilitation Division; (2) information in the DDA's physical files and electronic case management system (MCIS); (3) information obtained from the agency's Service Coordinators and provider staff; and (4) information in the DDS OGC's case files.

Over the two last years, systemic improvements have been made that will provide more real-time accuracy to the substitute consent information in MCIS. Periodic manual review and updates will always be necessary given that the needs of people and the status of the substitute decision-makers will continue to change going forward and given that the Court's data does not automatically link to or update MCIS's data. The most recent monthly review identified a number of previously-unidentified guardians, most of whom were family members who applied and were appointed prior to intake with the DDS. All the numbers provided below are an approximation because the numbers fluctuate from day to day as individual needs continue to change.

The following table provides a recent snapshot from data in MCIS as of September 30, 2018, which covers the 2,394 people supported by the DDA.

Independent Decisions	340
Presumed Capacity	282
Supported Decision-Making	121
Durable Power of Attorney	13
21-2210 Medical Decision-Maker	835
Mental Habilitation Advocate	2
Limited Medical Guardian	322
General Guardian	473
Old-Law Conservator	1
Guardianship in Progress	5

As indicated in the table, DDA records indicate that 473 people currently have a court-appointed general guardian and one person has the equivalent old-law conservatorship of the person, which is due to be converted to a general guardianship in October 2018. Moreover, 322 people have a limited medical guardian while two people have medical decision-making assistance from their court-appointed Mental Habilitation Advocate. Finally, five people are in the process of obtaining an appropriate guardian.

The DDA continues its efforts to identify people who have capacity to execute a durable power of attorney so that they might be offered the opportunity to select someone to assist them with decision-making. However, it is important to note that, though some people have been identified as having capacity to execute a durable power of attorney, they may not have any family or friends involved in their lives who are able or willing to support them with decision-

making. In those situations, the DDA may ask the Court to appoint a guardian if the person requires decision-making assistance. In addition, it appears that not many of the people served by the DDA have durable powers of attorney in place, most likely due to the other statutory and social options for decision-making supports. The DDA does not keep formal statistics on the numbers of durable powers of attorney offered or declined as these are personal decisions on the part of people supported by the agency. Over the last year, the DDS began to develop better methods for documenting existing durable powers of attorney whenever information is voluntarily shared by the person or an attorney-in-fact. The DDS OGC reviews incoming durable powers of attorney to give the agency a legal opinion about the validity of the documents. MCIS currently lists 13 people as relying solely on a durable power of attorney to obtain decision-making support. There are seven other people who are identified as making independent decisions, needing support to make decisions, or having presumed capacity, who all have also executed a durable power of attorney in case they need assistance. The DDS will continue to collect data as it becomes available.

While taking into account the preferences of the person supported, the DDS aims to identify family members or other people to provide assistance with supported decision-making when needed. To the extent these identified supporters are reasonably available, mentally capable, and willing to provide substituted consent pursuant to D.C. Official Code § 21-2210 (§ 21-2210 SDM), they may be called upon to provide more formal medical decision-making if supported decision-making is not possible. It is important to emphasize that those listed as having a § 21-2210 SDM may make many of their own decisions, with or without support, and may simply rely on the designated § 21-2210 SDM in certain situations. MCIS snapshot data shows approximately 340 people who make decisions independently, 121 people who make decisions with support, and 835 people who have a § 21-2210 SDM identified and available to act when needed. There are 282 people (a majority of whom live in their own homes, either with family or independently) who are presumed to have capacity under the law. The DDS notes that, of those 121 people needing support and those 282 presumed to have capacity, almost all have family or other supports to assist in their individual circumstances.

Furthermore, of the total 2,394 people served by the DDA, MCIS lists 31 people as having conservators, private trustees, or special/temporary conservators for decision-making related to finances. The conservators, private trustees, or special/temporary conservators may be appointed alone or in addition to the decision-maker listed in the chart above. This number is likely lower than the actual number of people who have an appointed conservator, trustee, or special/temporary conservator because the DDA does not currently have the level of access to court records for conservators and private trustees as it does for guardians. This number also does not count people with a pooled special needs trust under Shared Horizons's Wesley Vinner Memorial Trust. However, the numbers listed do reflect an improvement in the overall self-reporting and tracking of this information over the past year, and the DDS's plans to further document this type of information are detailed in the Annual Plan section below.

As stated above, the DDS and the DDS OGC work diligently to identify people who are in need of decision-making support. As a part of this effort, DDA Service Coordinators and

providers have been trained to review decision-making needs every year at the Individual Service Plan (ISP) meeting and to request additional capacity assessments as needed to consider the least restrictive way to support a particular person who requires decision-making assistance. A revised digital ISP format, which went live on October 1, 2017, aided significantly in tracking efforts for FY 2018 by providing sections for Service Coordinators to input more detailed decision-making information and send automatic ticklers to the DDS OGC for assistance when clarification is needed. This new tickler system has allowed the DDS OGC to review, and correct where needed, over 2000 questions regarding decision-making information in MCIS over the last year.

B. Aggregate Statistics for FY 2018

The reporting requirements in D.C. Official Code § 7-1305.07a(b) and (d) (2013 Repl. and 2017 Supp.) provide that the DDS should report the following aggregate statistics for FY 2018: (1) the number of substituted decisions that required intervention by the DDS to identify a substitute decision-maker to provide informed consent pursuant to D.C. Official Code § 21-2210 (already referred to herein as “§ 21-2210 SDM”); (2) the nature of the health-care needs and medical treatments; and (3) the average time elapsed between the request for a substituted decision and the provision of substituted consent. In examining the data from the end of FY 2017 and FY 2018, MCIS data lists approximately 32 of the § 21-2210 SDMs whose information was newly added to MCIS in the reporting period. The data shows that 14 people identified in FY 2017 as having a § 21-2210 SDM received guardians in FY 2018, and two people have a guardianship pending. Four people had their capacity designation changed to “presumed capacity” and 21 people had their DDS services end. The DDS becomes involved when a decision-maker has become unavailable or unwilling to assist the person in an appropriate or timely fashion or if there is an issue of abuse, neglect, or other inappropriate conduct.

During FY 2018, the DDA petitioned the Probate Court to obtain court-appointed permanent guardians for 21 people, 12 of whom received general guardians and five of whom received a limited medical guardian. Of those 21 people, the DDA first obtained a temporary guardian for four of them, using the Probate Court’s emergency process and keeping within the urgent and emergency timeframes set by the agency’s policy guidelines. One of the 21 petitions was dismissed for lack of jurisdiction and another petition was voluntarily withdrawn by the DDS because a family member agreed to comply with agency rules. Of the 21 petitions, two people still await appointment of a guardian with their initial hearings scheduled timely in October and November of 2018. The DDA also obtained the appointment of general guardians in proceedings for two people whose guardianship petitions were filed during FY 2017 (the reporting period for the previous Annual Report-Plan) and one of those people also received a conservator to assist with potential financial exploitation.

Beyond the hearings for new guardians initiated by the agency, the DDS participated in at least 87 guardianship-related hearings, some initiated by the DDA and others by the Court, family or by other District agencies regarding people served by the agency. Within those 87 hearings, the DDS initiated and/or became heavily involved in two petitions for removal of a

substandard or under-performing guardian, one of which led to a mediation and three-day evidentiary hearing regarding vaccinations. The DDS participated in at least 24 status hearings set by the Court on its own initiative or at the request of the Probate Court's Guardianship Assistance Program (GAP) to address an issue found during its spot check reviews. To give some perspective, the issues covered in these hearings were wide-ranging. For instance, two hearings were before the Auditor-Master for a continuing trust issue for two siblings served by the DDS; nine hearings were for new petitions for guardianship filed by family members; seven hearings were requests for emergency 21-day or 90-day guardians (two of which were regarding end-of-life issues and one regarding an out-of-state placement issue); three hearings involved the Court's latest initiative to identify and reexamine guardianships for people placed outside of the District of Columbia; four hearings involved financial issues or exploitation; six hearings were held about resigning guardians or conversion of a guardianship; six hearings were for families or a ward seeking the removal of the guardian; one hearing was for the termination of the guardianship; two hearings were to move the person to another jurisdiction; and four hearings were to expand the guardian's powers. It is noteworthy that the number of these additional types of hearings have steadily increased every year for over the last five years and far exceeds the number of initial proceedings initiated by the DDS. This increase reveals that the DDS has spent more time in the maintenance and adjustment of existing guardianships over the last fiscal year than in initiating new guardianships, but also signals the Court's increased efforts toward checking on guardianships in progress, which will be discussed further in upcoming sections. For reference, the DDS has been interviewed for, received, and/or reviewed approximately 101 case reviewer (formerly known as "staff visitor") reports in FY 2018, with some of the reports leading to 13 of the status hearings held.

C. FY 2018 Statistics and Annual Trends

As in prior years, the DDS consistently tracked data on guardianships in FY 2018. For all instances where it is necessary for the DDS to obtain a guardian, the DDS tracks the time elapsed between the following stages in the process: (1) the days elapsed between the date that the DDS Service Coordinator is notified of the need for a guardian and the date that the guardianship request package is submitted to the DDS OGC; (2) the days elapsed between the date that the guardianship request package is submitted to the DDS OGC and the date that the petition is filed with the Court; and (3) the days elapsed between the date that the guardianship petition is filed with the Court and the scheduled hearing for a guardian.

During stage 1 ("Identification of Need" through "Submission to the DDS OGC"), a comparison of statistics between FY 2017 and FY 2018 shows improvement in the average, but the median somewhat negates that result. The average indicates that compiling and submission of guardianship request packages were completed 8.4 days more quickly in FY 2018 than in FY 2017. However, packages in FY 2018 were submitted on median within 45.5 days, which is 10.5 days slower than in FY 2017. This contrast between the average and the median may be explained by the wide range of the data, given that the quickest submission took only two days but the longest took 314 days. Discussion of the DDS initiatives for further improvement in this

stage, particularly plans for minimizing the types of extreme outliers in this stage, are included in the Annual Plan section of this report.

During stage 2 (“Submission to the DDS OGC” through “Petition Filed with the Court”), both the median and the average number of days elapsed show improvement in time elapsed. Over this past year, the average number of days used to process and file packages improved by approximately three days and the median improved by two days. Thus, packages were processed in this reporting period were filed, on average, within three days of submission to the DDS OGC. The DDS OGC will strive to maintain its efficiency in this area while balancing the increasing number of complex guardianship issues arising post-appointment.

During stage 3 (“Petition Filed with the Court” through “Scheduled Hearing/Appointment of Guardian”), the median days elapsed has remained fairly consistent for the last few fiscal years. It is important to note that, for the last three years, the Court has four sitting judges to help handle the ever-increasing docket and this past year saw the introduction of a Magistrate Judge to the Probate bench as well. The Court’s average time for setting a hearing has improved by approximately five days and the median has improved by two days. The DDS OGC and the Probate Division have fostered a strong communication strategy to ensure that the Probate Division can meet the needs of people as they are identified by the DDA and to ensure that the DDS OGC can file initial pleadings quickly in a way that does not overburden the Probate Division’s limited administrative staff.

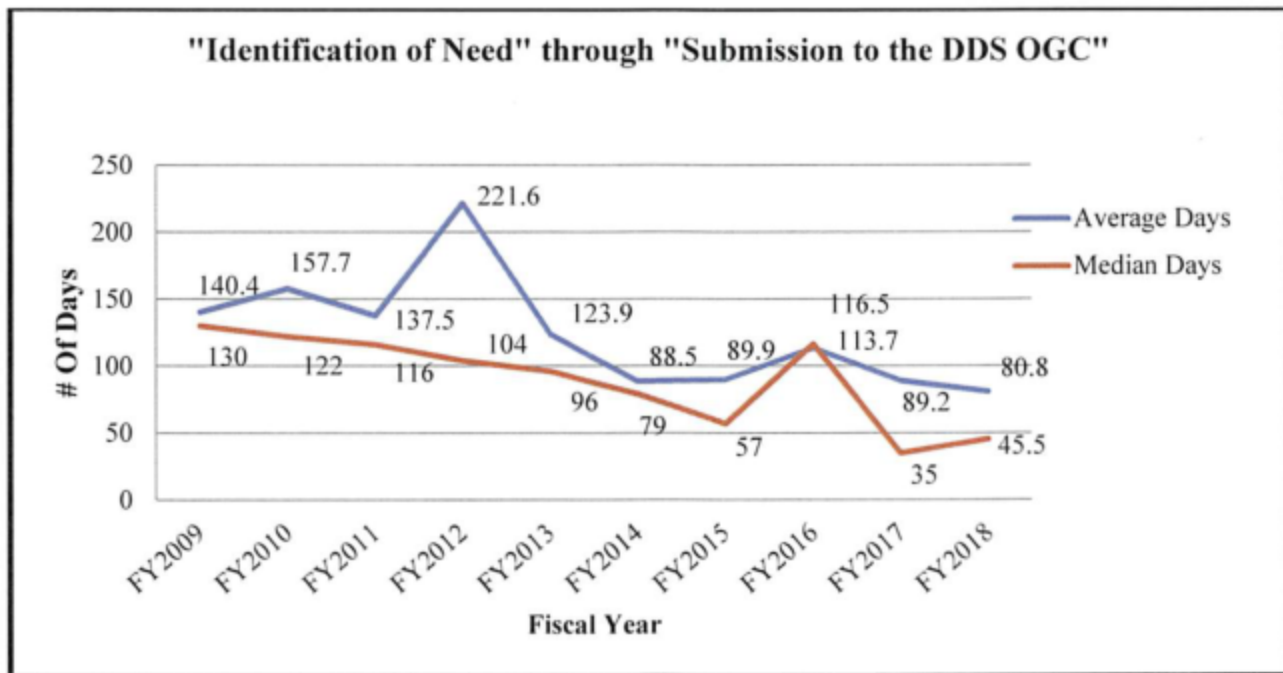
Though not included in the statistics, urgent and emergency situations are being triaged and addressed efficiently, often obviating the need for filing of an emergency petition because another appropriate and expedient solution has been found. In FY 2018, the DDS petitioned to obtain a temporary guardian for four people through the Probate Court’s expedited process, keeping within the timeframes set by policy guidelines. The DDS also participated in one other emergency hearing, which was filed by the hospital, and two involving end-of-life decisions. Notably, the Court has been willing to appoint temporary guardians, allow temporary guardians to make residential placement decisions, and instruct attorneys to consider applying for protective orders as a preventative measure when the Court’s needs require a case to be continued over a long period of time.

The graphs on pages 7 and 8 show the changes in the average number of days taken for a package to move through the processing stages from FY 2009 through FY 2018. Starting in October of 2009, the DDS began to provide both the statistical average and the median, taking note of outliers and small sample sizes, to provide more precise and representative statistical analysis.²

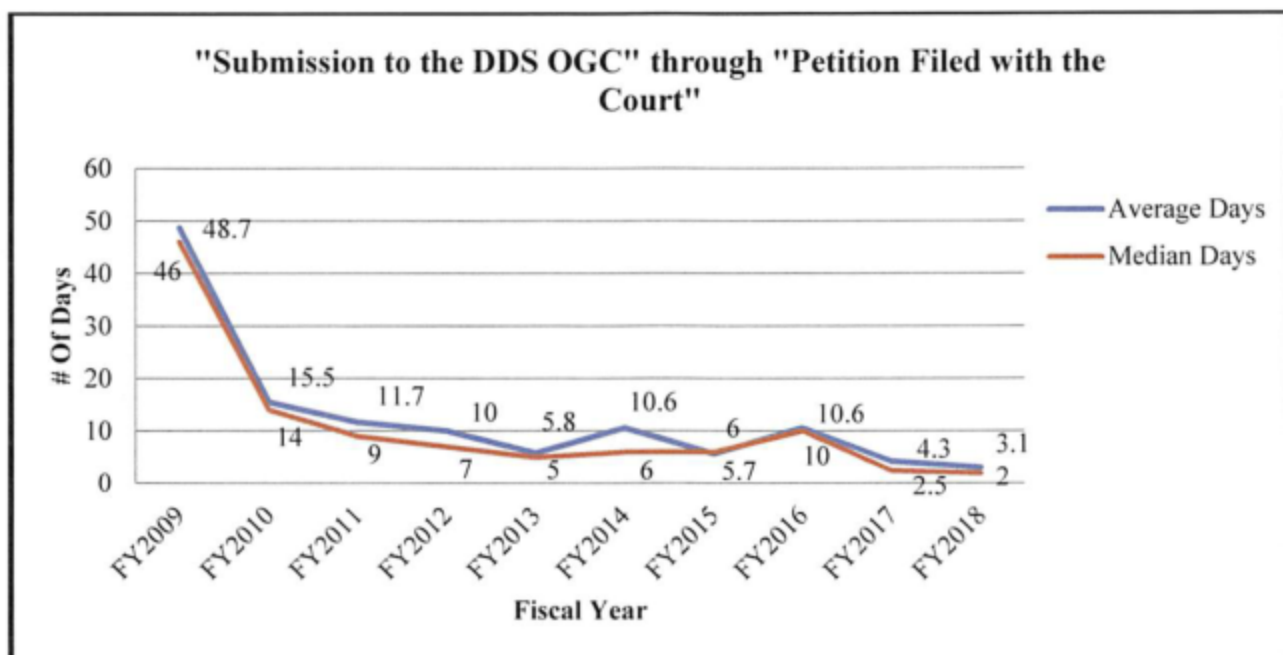
² The 2012 statistics for stage 1 indicate a large difference between the average and median days elapsed. This was due to a very small sample size and a large range.

Comparison of Annual Statistics for Days Elapsed in the Guardianship Process

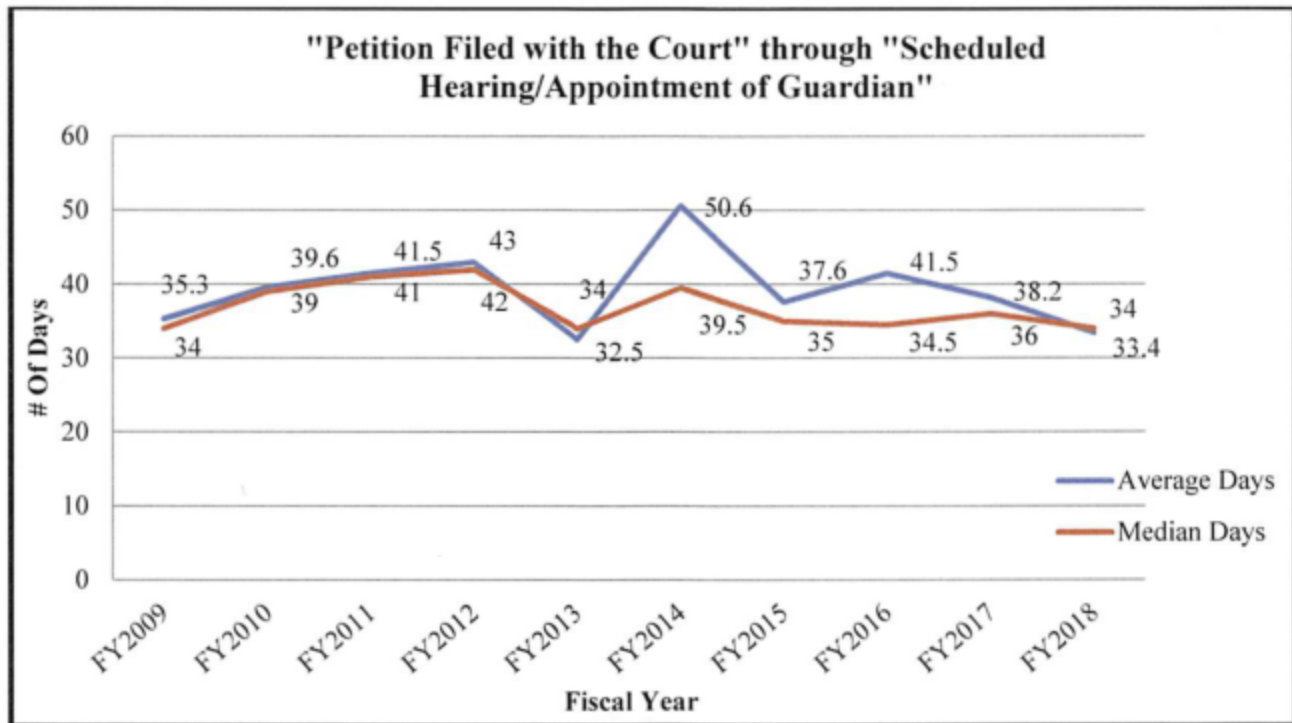
Stage 1:



Stage 2:



Stage 3:



II. PSYCHOTROPIC MEDICATION

The reporting requirements in D.C. Official Code § 7-1305.07a (b) and (d) (2013) provide that the DDS should report the following aggregate statistics for FY 2018: (a) numbers of people taking psychotropic medications as of the end of the previous fiscal year, and an assessment of the degree to which health-care decision-making support for the prescription of psychotropic medication may be required for these customers; and (b) requests for consent reviewed during the prior fiscal year by the independent psychotropic medication panel authorized by § 506b of D.C. Law 17-249, analyzing outcomes, monthly and yearly trends, and requests for review by the DDS Human Rights Advisory Committee (HRAC).

A. Identification of People Taking Psychotropic Medication

According to Service Coordination monitoring results collected throughout FY 2018, there were 881 people for whom a physician or psychiatrist had recommended treatment with at least one psychotropic medication.

The person's ISP team and treating physicians are responsible for reviewing the documentation, prescriptions for medications, and possible side effects of the prescribed medications with the person. Provider Human Rights Committees are responsible for reviewing the efficacy of all restrictive controls, including psychotropic medication to determine whether such use is appropriate and/or effective. The ISP team is responsible for on-going tracking and

review of the medications, making recommendations as part of daily medication monitoring, and monthly medication reviews.³

The DDA tracks review of all people on psychotropic medication in relation to the existence of a Behavioral Support Plan (BSP). The DDA has monitored the use of psychotropic medications through monitoring by Service Coordinators, registered nurses from the DDA's Health and Wellness Unit, and the Restrictive Control Review Committee (RCRC), a subcommittee of the DDA's HRAC. Most people who take psychotropic medications are required to have a BSP, which includes positive strategies to reduce the reliance on medications to manage behaviors. If a person is taking only one psychotropic medication and meets certain other criteria, they are offered the opportunity to opt out of having a BSP via the BSP exemption process. To avoid overmedication and drug interaction issues, the DDA expects providers to routinely report the effectiveness of the medications through data to the psychiatrist and monitor side effects using standardized tools such as the Monitoring of Side Effects Scale (MOSES) or the Abnormal Involuntary Movement Scale (AIMS).

Service Coordinators conduct routine monitoring for all people receiving services who take psychotropic medications to determine if: (1) people who take psychotropic medications have BSPs; (2) the provider has evidence of consent by the person or the legally authorized representative; (3) the psychiatrist reviews the behavioral data and use of medication quarterly; and (4) screening for tardive dyskinesia is conducted at least every six months using a standardized tool, such as the AIMS or MOSES, by a qualified health-care professional. Monitoring indicates a high compliance with these protections in FY 2018, generally in excess of 90% of the time. The Service Coordinator also ensures that the BSP has been reviewed by the provider's Human Rights Committee. Monitoring indicates that providers were compliant with this assurance approximately 94% of the time in FY 2018, which shows an increase in compliance from FY 2017.

At the conclusion of FY 2018, there were approximately 547 people who had active BSPs that included psychotropic medication. Seven others had active BSPs for other reasons such as behavioral supports or restrictive controls not involving psychotropic medication. Of the total 547 active BSPs, the RCRC reviewed approximately 537. Of the 537 reviewed, approximately 491 (91%) of the plans that included psychotropic medications have been approved. The RCRC process evaluates the rationale for the use of the restrictive intervention, the efficacy of the plan for reduction of the restrictive intervention, the inclusion of positive strategies to enhance skills and address target behaviors in the least restrictive means, and whether the plan is consistent with established DDS policies and procedures. The RCRC can approve a plan, reject a plan if it is unsafe to implement, or defer a plan if there is not enough information to make a decision. When a plan is approved, the BSP can be implemented safely for

³ At this time, the DDA cannot track medications for people in natural homes (people who live in their own homes or with their family/other primary care-giver) and completely independent settings unless those people or their families are willing to share their medication information with the agency. The use of psychotropic medications for people residing in natural home settings is often learned by accident or when the person elects to transition to supported living, residential habilitation, or an intermediate care facility setting.

up to two years. In the event that a BSP is rejected, deferred, or in the queue for RCRC review, providers are instructed to continue following physician's orders as they relate to supporting people in taking medications. Per the DDS's policy, they can also continue to implement the last BSP approved by the RCRC.

In the past, the DDS has invited providers, clinicians, attorneys, and guardians to attend trainings about the dignity of risk and person-centered thinking, conducted by Michael Smull of Support Development Associates, to help encourage appropriate frameworks for BSPs. The DDS Office of Rights and Advocacy continues to conduct these and similar trainings for clinicians, providers, and provider HRCs to further ensure that BSPs are developed in accordance with DDA policy and best practices.

B. Independent Psychotropic Medication Panel

The DDA Procedure Number 2013-DDA-H&W-PR016, effective September 3, 2013, states that, "[i]f a person has been legally certified to not have the capacity to consent for the use of psychotropic medications, and there is no substitute health-care decision-maker available, the DDS Psychotropic Review Panel may authorize the use of psychotropic medications for up to nine consecutive months." In FY 2018, there were no emergency issues that required the Psychotropic Medication Review Panel to be convened.

ANNUAL PLAN FOR FY 2019

I. SUBSTITUTE CONSENT AND GUARDIANSHIP

In planning for FY 2019, the DDS will continue its efforts of consistent and accurate collecting and tracking of information about capacity, consent, and decision-making for people supported and served by the DDA. The digital innovations implemented in the last year provide more opportunity and systematic support for our efforts. The DDS will push forward with more education and follow-up support for its staff who enter and collect the information as well as periodic internal review of the collected information as a quality check.

During FY 2018, the DDS raised the standard on a number of its long-standing initiatives regarding identification and, when necessary, appointment of substitute decision-makers for people served by the DDA. The DDS emphasizes the importance of assessing a person's capacity to make all types of decisions so that the DDS may find assistance for people in the least intrusive and least restrictive ways. The DDA encourages Service Coordinators and providers to utilize supported decision-making to the greatest extent possible and, when that is not possible, consider how best to support lesser restrictive types of substituted decision-making, leaving guardianship as the last resort. Recent changes in the law, as detailed below, have provided more legal backing for supported decision-making as a viable option with financial and medical institutions, and the DDS is taking an active role to ensure that supported decision-making is recognized and used by the community. This determination to find the least restrictive option does, on occasion, cause a DDA Service Coordinator to continue to pursue family or

friend options for a little longer, rather than immediately pursuing the appointment of a guardian when a family member becomes unavailable. The efforts to work with family are typically one of the main sources of delay, albeit justifiable and appropriate delay, in starting the guardianship process.

Regarding the guardianship process, the focus must remain on Stage 1. The DDS believes improvement will come from progress in three areas: (1) comprehensive understanding of the process by Service Coordinators and provider staff; (2) efficient triaging of issues; and (3) the consistent availability of knowledgeable DDS OGC staff and Supervisory Service Coordinators to advise Service Coordinators with individual issues and questions during this initial portion of the process.

In the past, Stage 1 delays have been primarily due to the need for assessments, declarations, or affidavits from the medical and psychological professionals in the community. While this can still be a cause for delay for some packages, there is an increasing number of guardianships which evolve from complex situations, such as clinical disagreements about capacity or issues with family members that required constant re-evaluation about whether guardianship would be possible or needed. The guardianship process instructs provider staff and DDA Service Coordinators to seek assistance from the DDA administration and the DDS OGC on a case-by-case basis when there are complex situations. Thus, determining a quick course of action is dependent on how quickly provider staff and DDA Service Coordinators elevate issues for assistance.

As noted above, delays can still be caused by the need for updated or clarified psychological assessments, or “current” declarations or affidavits. Conducting annual psychological assessments are not considered clinical best practice, thus the person’s support team should request psychological assessments or updates whenever deemed necessary. Obtaining “current” declarations or affidavits from clinicians is essential to the process as well, as the Court is required to consider a person’s current capacity and has, at times, considered even a six-month old declaration as out of date. The clinicians involved must complete the requisite psychological testing, review records, and make a number of visits to produce a thorough assessment with a clear capacity statement. In the last year, psychological assessments have taken months to obtain because of the limited number of clinicians available to provide this service and the time needed to produce a thorough assessment. The DDA continues to focus on attracting new clinicians with the expertise and time to devote to our system. The DDS OGC includes information in training to remind support teams to remain vigilant of changes in capacity and request updates at that time rather than requesting an update when a potential guardianship need arises. These assessments are the best indicators of a person’s need for support in decision-making, and must remain current and accurate, so that support structures can be appropriately tailored.

Another source of delay, obtaining notarized affidavits from clinicians, has become a moot issue. In 2011, a rule was implemented in the Civil Division of the D.C. Superior Court that considers declarations, which are testimonial statements not requiring notarization, as

equivalent evidence to affidavits. The DDS OGC continues to urge the Probate Court to adopt a similar rule to provide clarity. The Probate Court has not yet adopted a similar rule for general proceedings but may do so in the future given the recent implementation of e-filing in the Probate Division. Despite the lack of a formal rule, the DDS OGC has phased in the use of declarations and has been successful in a number of emergency, urgent, and permanent guardianship proceedings. The latest version of the DDA policy on Decision-Making Supports normalizes the DDA's use of declarations in lieu of affidavits. Thus, the main source of delay in this area comes from the instances where the clinicians are unwilling to provide the declaration or any other written testimony.

In addition, the DDS continues to prioritize initiatives which promote the health and improvement of the overall systems of decision-making supports for people served by the agency – particularly those programs related to the health-care system, the various options for substitute consent, and the Court's guardianship programs. Updates on previously implemented initiatives and future plans are included below.

A. Dedicated Attorneys from the DDS Office of the General Counsel

For the past few years, two attorneys from the DDS OGC have served as full-time points of contact for Service Coordination, the Probate Division, substitute decision-makers, other attorneys, and even hospital professionals regarding substitute consent issues and guardianship. The DDS OGC continues to provide support for attorneys at the Child and Family Services Agency (CFSA) regarding substitute decision-making so that they can ensure that CFSA's youth between ages 18-21 have needed assistance. In addition, the DDS OGC attorneys will remain in touch with colleagues from both the Department of Behavioral Health and Adult Protective Services to coordinate efforts for people served by multiple agencies. The establishment at the Office of the Attorney General of the District's first Elder Abuse Prosecutor position promises to provide more support for agencies when helping vulnerable and exploited elders. The DDS OGC intends to foster a mutually-helpful relationship there as well.

The DDS OGC, through its two assigned attorneys, will continue to bear the responsibility for processing all of the guardianship petitions for the DDA as well as participating in hearings for petitions filed by family members for people supported by the DDS. Given the trends of the last four years, the majority of their efforts will be spent handling matters involving petitions post-appointment filed by current guardians and removal of guardians, which, are certainly more time consuming than the initial guardianship appointment hearings. As a part of those efforts, the DDS OGC will continue to work toward issue resolution with guardians through correspondence, meetings, and mediation when necessary. In extreme circumstances, the DDS OGC will file for the removal and replacement of guardians.

The DDS OGC will continue to assist the agency with monitoring information and updating tracking procedures as well as providing these annual report-plans to the D.C. Council. Along with issue resolution, the two attorneys will focus as much time as possible on ensuring updates of the data in MCIS. Three projects that continue to require attention and time involve:

(1) the filing of motions with the Probate Court to ensure that the DDA is listed as an interested party in all guardianship cases so that the DDA will receive timely notice of hearings, guardianship reports, and updates on changes to guardian appointments; (2) the scanning and saving of the DDS OGC's hard copy files; and (3) working to improve data collection mechanisms in MCIS regarding durable powers of attorney, special needs trusts, conservatorships, and supported decision-making. The DDA's party status and digitizing the legal files have both become more pressing once the Probate Division began to mandate electronic filing, and party status has become particularly important because of the GAP's dramatic increase in review of guardianships as detailed below. In the past year, the DDS OGC made significant progress towards minimizing the backlog on both party status filings and digitizing documents. Going forward, the majority of the filing will be petitioning for party status in new cases and scanning incoming new documents regularly.

The assigned attorneys remain committed to growing their skills to assist the agency in developing areas. In FY 2017, the attorneys sought out more information about end-of-life planning and powers of attorney and, throughout FY 2018, began to offer training in those areas for agency and provider staff. The training also provides comprehensive information for the agency on existing forms regarding substitute consent as well as newly-developed templates on powers of attorney and living wills. Participation in the District's first ever Institute on Aging in D.C., held on September 20, 2018 at the D.C. Bar, provided networking and new information that will grow the office's practice and access to resources. The attorneys continue to develop their mediation technique given the Probate Court's increased referrals to mediation in guardianship conflicts. Guardianship and consent issues continue to provide opportunities to research and make arguments on a wide array of topics relating to the rights of people supported by the DDS.

B. Tracking Initiatives

Through the teamwork of the DDS OGC, the DDA's Service Coordination and Planning Division and the DDS Office of Information and Data Management, the DDS continually re-examines the DDA guardianship request process to remedy inefficiencies. Since FY 2010, emphasis has been placed on notifying the DDA's Deputy Director's administrative staff of guardianship needs as soon as they are identified so that the Deputy Director can better monitor and request assistance for Service Coordinators until the final package is submitted for supervisory review. In this way, the DDA can gather data on prevalent issues and obstacles during Stage 1 and notify the DDS OGC if specific assistance is needed. While the agency has contemplated a number of electronic methods of ensuring this information is accurately captured, including the idea of an electronic routing form linked to MCIS with automatic email reminders, many of the ideas were put on hold because of an overarching plan to replace the DDA's case management system with a multiple agency system. However, it is now envisioned that MCIS will continue to be the home of the substitute consent and guardianship information. The new digital version of the ISP also provides user-friendly means for Service Coordinators to check a box and have questions directed automatically to the DDS OGC for assistance in this area.

Currently, MCIS includes a side tab labeled “Substitute Consent” and the information in the database is available for viewing by all authorized agency and provider staff. The DDS OGC continues to methodically research, review, and correct substitute consent information for people as explained elsewhere in the Annual Plan. As the data continues to be updated, the DDS can more accurately report on the statistics mandated in the reporting requirements and, more importantly, can have a more accurate number of people who still require assistance with decision-making. Of course, these numbers constantly change as capacity changes, decision-makers become unavailable, and/or new decision-makers are identified. The DDS OGC reviewed and revised over 2000 pieces of information in MCIS this year and can more confidently believe that a baseline of correct information has been accurately established and maintained. Thus, the DDS OGC simply must ensure that needed changes are continually tracked and updated appropriately going forward. In addition, the assigned DDS OGC attorneys maintain an issue chart to track all substitute consent and questions raised by agency staff and to ensure timely resolution.

After identifying the trends of incomplete or inaccurate information in MCIS and figuring out the teams that enter information in specific areas, the DDS OGC attorneys and DDA Intake created a process to ensure that the DDS OGC attorneys are aware, in real time, of people found eligible through Intake so that substitute consent information can be researched and inserted into MCIS for the service coordinator assigned the new person. In just the first year of this process, the amount of incomplete information has been drastically reduced – which became apparent when compiling the information for this annual report and plan. In addition, the OGC attorneys have conducted trainings and had conversations with the Supervisory Service Coordinators to discuss how to read and store capacity assessments, how to properly enter substitute consent information and the changes to the new ISP involving substitute consent, as well as trainings for Service Coordinators about new court processes regarding assessments. There are plans for continuing these conversations in small group settings with Service Coordination teams as well.

Though the DDS website already contains all current policies and procedures, the DDA plans to supplement the policy in this area with fillable guardianship and substitute consent forms (rather than the PDF versions available now) as well as making those documents available in MCIS, now that it is certain MCIS will continue to house this information. There have also been ongoing discussions about the best way to place these documents into the DDS Provider Portal as well as into electronic medical records systems used by various provider companies so that they will be more available to the medical and provider community.

C. Legislative and Policy Revision

The Substitute Decision-Making Policies and Procedures covering emergency, urgent, and non-emergency situations have gone through a number of stages of revision with the most recent version signed in January 2015. The emergency and non-emergency policies have been combined into one comprehensive draft policy, with updates for People First language and with more emphasis on the concept of supported decision-making rather than only focusing on substitute decision-making. The draft “Supported Decision-Making Policy and Procedure” has

been reviewed by the DDS Policy Review Committee, which is comprised of self-advocates and community stakeholders. After noting their concerns and comments, the DDS made revisions and brought the policy back to the group for discussion. Given recent legislative changes discussed below, the comprehensive policy and procedure require more revision before eventual approval by the DDS administration.

On August 3, 2018, the “Disability Services Reform Amendment Act of 2018,” (DSRAA) went into effect. Title II of the DSRAA, codified at D.C. Code §§ 7-1301.01 *et seq.*, comprehensively repeals and amends various sections of the “Citizens with Intellectual Disabilities Constitutional Rights and Dignity Act of 1978” (D.C. Law 2-137), such that there will be no Habilitation Court involvement for people newly-found eligible for DDS services and no new civil commitments of people with intellectual disabilities, with the exception of people found incompetent in criminal cases. The DSRAA also specifically amends Section 411(a) of D.C. Law 2-137, in pertinent part, to require the Court to terminate the commitment of a person with an intellectual disability, other than a person found incompetent in a criminal case, at the annual review hearing unless the person or an authorized substitute decision-maker “provides informed consent to continue the person’s voluntary commitment.” The subject of the Habilitation proceeding is presumed to be capable of consenting to or refusing continued commitment. However, to the extent the person lacks capacity to give informed consent, the DSRAA identifies a hierarchy of nine people authorized to consent on the person’s behalf. At the top of the hierarchy are court-appointed general guardians and limited medical guardians.

The DSRAA’s secondary aim is to provide formal recognition for supported decision-making for people with disabilities with the creation of a Supported Decision-Making Agreement (SDMA). Although supported decision-making is mentioned above, it may help to know that the new law defines supported decision-making as a mechanism whereby unpaid supporters may help a person with disability to gather, understand and consider relevant information about the decision in question, assist the person to weigh pros and cons, predict likely outcomes and consequences, or evaluate the available options.

The implementation of the DSRAA by the Court has involved a partnership between the DDS OGC, the Presiding Judges of the Family Court and the Probate Court, and various stakeholders. The DDS OGC and the DDS State Office of Policy, Planning and Innovation (DDS SOPPI) worked together to provide in-house trainings about the changes to the Court processes and the implementation of supported decision-making for agency staff and providers on April 12, June 1, and June 13, 2018. In addition, the DDS OGC was pivotal in planning training for Habilitation Panel, Fiduciary Panel attorneys, and other types of guardians. This training, held on June 1, 2018, was designed to provide information about the voluntary commitment process, and tips for advocacy to ensure that the committed people in question would have the appropriate support to voice their wishes.

The Supported Decision-Making title of the law took immediate effect, meaning that beginning on May 5, 2018, D.C. residents with disabilities had expanded rights associated with this key decision-making approach. Prior to the passage of the DSRAA, the DDS SOPPI highlighted this new aspect of the law at monthly meetings of the self-advocacy group Project

ACTION!, the Family Support Council (described below), and a variety of other community groups, including the Supporting Families Community of Practice, the Secondary Transition Community of Practice, the Long Term Care Coalition, and the Georgetown University Center for Excellence in Developmental Disabilities Community Advisory Committee. These conversations took place through FY 2018, and are planned into FY 2019, at regularly scheduled meetings of our partners; that is, rather than holding new meetings and asking stakeholders to come to the DDS, we went into the community and asked to be included on the agenda for their meetings.

The DDS SOPPI serves on the Planning Committee for the DC Supporting Families Community of Practice (DC SFCoP) and provides ongoing support for those quarterly meetings. On June 14, 2018, the DC SFCoP held a day-long training event for self-advocates and community members on the DSRAA. Training on all three titles of the law was provided: the DDS OGC trained about commitment, Quality Trust (QT) trained on supported decision-making, and the DDS SOPPI trained on a new grievance system under development. Education about these new processes have been crucial for ensuring that the implementation of the DSRAA goes smoothly and meets the legislative intent of the law. On Friday, September 14, 2018, the DDS and other Planning Team members arranged for the SFCoP to continue discussion during its day-long meeting on when and how to use supported decision-making, led by QT. The DDS will use the information gleaned at this meeting to develop a tool for families to use in planning for supported decision-making.

The DDS SOPPI has taken the lead to generate a SDMA for the D.C. government in compliance with the new law. For supported decision-making to be well-understood, and for SDMA's to be used properly and respected appropriately, the DDS partnered with QT to combine the required form with information about supported decision-making and instructions on how to complete the form. To ensure readability and usability, the DDS SOPPI and QT asked the Family Support Council (FSC) and the self-advocacy group Project ACTION! to review the materials, and the form and information went through legal sufficiency review with the DDS OGC. The FSC is a group of 11 family members of people with disabilities and people with disabilities themselves who are appointed by the DDS Director to assist, advise, and provide recommendations to the DDS and sister agencies on developing person- and family-centered supports, which include self-determination and support for making informed choices. Importantly, the FSC advocated for the passage of the DSRAA and is committed to expanding supported decision-making in the District across a person's lifespan.

The DDS SOPPI provided an early, usable version of the SDMA to partner agencies on June 10, 2018. A further refined version was completed in conjunction with QT on July 17, 2018. The DDS OGC and the DDS SOPPI provided training on supported decision-making and the new commitment processes during a webinar for partner agencies on July 19, 2018. Those agencies, including the DDS, the Department of Behavioral Health, the DC Department of Health (DC Health), and the DC Office on Aging (DCOA), then attended the July meeting of the FSC, to share ideas about how to best implement supported decision-making in the District.

The DDS made the more accessible version of the SDMA and instructions available on the newly updated Decision-Making Rights pages of the DDS website.⁴ The website revisions went live on August 30, 2018. The DDS SOPPI is finalizing a booklet edition which will be available in digital and, budget permitting, print format in FY 2019.

During August and September 2018, the DDS SOPPI supported the Family Support Council to apply to undertake a year-long effort to create and pilot a supported decision-making structure at the DDS and DCOA. This will be adapted and rolled out to community partners and the other District government agencies that serve youth with intellectual and developmental disabilities (I/DD), older adults, and families and that are advised by the FSC. The FSC will serve as a convener and facilitator to bring together decision-makers and stakeholders to guide the process of crafting a structure for supported decision-making and its continued roll-out at key District agencies. Training on best practices will be designed and shared with people with disabilities, families, community providers, and state staff. Stakeholders will contribute to the design of these trainings so that they would be useful for anyone who might play a role in supported decision-making in the District. The FSC will convene focus groups on opportunities and perceived barriers to supported decision-making so that youth, adults and elders with disabilities; family members; service providers; and state staff play a role in shaping this cross-agency lifespan approach to supported decision-making.

The proposal received 17 letters of support, including letters from five District agencies; the District of Columbia Association of Special Education; the D.C. Commission on Aging; Project ACTION!; DC SFCoP; the D.C. Developmental Disabilities Council; Disability Rights DC at University Legal Services; Georgetown University Center for Excellence in Developmental Disabilities; D.C. Coalition of Disability Providers; D.C. Coalition on Long Term Care; East River Family Strengthening Collaborative; and Seabury Resources for Aging.

On October 3, 2018, the federal Administration for Community Living and the National Resource Center on Supported Decision-Making approved this project and the FSC's participation will be a part of a new national Community of Practice (CoP) on supported decision-making. The DDS will provide the FSC with financial support in this exciting FY 2019 effort to help bring the promise of the Supported Decision-Making title of the DSRAA to fruition. In partnership with the FSC, and through this technical assistance grant, we will be able to bring relevant agencies to the table, create structures and training to implement supported decision-making in our public and community programs, increase knowledge and understanding of supported decision-making and the DSRAA, and develop approaches so that people are supported in making decisions as needed in key areas in their lives, and that they are supported by people they choose.

In FY 2019, the DDS SOPPI will develop a train-the-trainer curriculum and hold additional trainings at District agencies on supported decision-making and this train-the-trainer model to expand knowledge and usage. Where possible, the DC SOPPI will coordinate with partners to facilitate trainings of self-advocates, stakeholders and the community at large. As a

⁴ Please see <https://dds.dc.gov/page/dds-decision-making-rights-people-disabilities>.

government agency, the DDS cannot provide legal advice about whether to use and how to complete legal documents such as the Supported Decision-Making Agreement template from the DSRAA. Leaving that work to disability rights advocates and attorneys in the D.C. Bar, the DDS will instead focus on ensuring that information and resources about the important advance in the law on decision-making rights expands in the coming year.

Outside of the DSRAA, other pieces of legislation may be important for the DDS's support of people in the D.C. community. On March 9, 2016, a bill creating medical orders for life sustaining treatment forms similar to those in use in Maryland, known as the "MOST" form in the District, was codified into law. The DC Health is working to create, provide training and implement the form, which would replace the concept of comfort care orders and bracelets. The DDS OGC followed the implementation of this process very carefully and offered assistance as well. In addition, a bill was passed implementing the "Request for Medication to End My Life in a Humane and Peaceful Manner" form and another bill has been proposed regarding uniformity for durable powers of attorney. Legislation regarding elder abuse tracking and monitoring is also pending before the Council. Again, all of these changes to the law are being followed carefully to see what impact they may have for people supported by the DDS.

D. Training Sessions on Substitute Decision-Making

In FY 2018, Decision-Making and Consent trainings for DDS and provider staff was scheduled and held on November 15, 2017; January 17, 2018; March 28, 2018; and May 22, 2018. Trainings were also scheduled for July 17, 2018 and September 20, 2018 but were both cancelled for low attendance. The next training is scheduled for November 14, 2018 and will be conducted in alternating months into 2019. Although the curriculum for in-house training sessions already includes detailed information about all forms of substitute decision-making and explores issues surrounding capacity, the DDS OGC has created an additional training on durable powers of attorney and advanced planning. The training was first presented to Supervisory Service Coordinators on January 30, 2018. More widely attended trainings were scheduled on April 18, 2018, and June 13, 2018 with the August 15, 2018 training cancelled for low attendance. The DDS OGC also held a special training on both topics for the DDS's Health and Wellness unit on June 8, 2018.

The DDS OGC trained the social work students and new staff visitors participating in the Probate Court's GAP on May 30, 2018 and continues to be available for the staff visitors as specific questions arise during their reviews.

The Court invited the DDS OGC attorneys to present information about the DDS system and its role in guardianship hearings to its newest judges for the Probate Division. The DDS OGC met with Associate Judge Jonathan Pittman on May 30, 2018. Associate Judge Darlene Soltys joined that session. On September 13, 2018, the DDS OGC met with Magistrate Judge Katherine Wiedmann for a similar presentation.

E. Communication with Hospitals and Health-Care Organizations

The DDS's partnership with the Georgetown University Center for Child and Human Development continues to highlight opportunities to train on and discuss decision-making with various health-care groups and hospitals in the community. Similarly, the DDS continues to explore ways that we can partner with hospitals on educational initiatives regarding decision-making and health-care, as we have done in the past.

In addition to formal presentations, the DDS OGC provides more intensive support to the agency and to guardians when issues arise in hospital settings regarding substitute consent. In FY 2018, the DDS OGC assisted in more than 15 different situations where substitute consent was an issue for a person in a hospital setting.

F. Guardian Education, Assistance, and Monitoring

The DDS places an emphasis on person-centered thinking processes and, for many years, has promoted the idea of supported decision-making. Supported decision-making presumes capacity for people served by the DDS so that substitute decision-making and guardianship are the options of last resort. The DDS's belief and experience has been that many people can make decisions, including health-care decisions, with support that enables them to understand their options and the potential outcomes, consequences, risks, and rewards of their decisions. The DDS also believes that the guardianship system could benefit from more recognition of person-centered thinking processes and supported decision-making. Presenters at the recent Institute on Aging provided some helpful information for attendees about supported decision-making in a presentation about the various options for decision-making support. Certainly, more education can be done by the DDS, its stakeholders, and the DDS OGC and much is being planned, as discussed above. The DDS continues to engage in different types of initiatives to promote education, assistance, and monitoring of guardians and the community.

The DDS's partnership with the Probate Division and other community groups on the WINGS grant – for the betterment of the guardianship system – came to an end with the last stakeholder meeting taking place on October 3, 2016. The WINGS stakeholder group represented a wide range of community groups and has provided all involved groups with a network of resources. The complaint procedure implemented through the WINGS project still remains in place and being used by the community. The DDS is hopeful that, given the popularity of the 2015 WINGS training sessions (which included sessions about supported decision-making and person-centered thinking for guardians), the Court may decide to make the session an annual occurrence, with the DDS and other stakeholder assistance. However, limited resources at the Court and at the DDS may cause some delay in such plans being implemented in the upcoming fiscal year. As discussed above, the DDS worked with the Probate Division over the last year on the education of guardians and fiduciary panel members on the DSRAA and supported decision-making.

The DDS, through the DDS OGC, has maintained a positive working relationship with the Probate Division and the Register of Wills. The DDS OGC and the Register of Wills continue to resolve process and research issues, and have discussed the DDS OGC's ideas about the guardianship system and the DDS estimates for future filings. In addition, the DDS OGC has been asked to participate in the Probate Court's Fiduciary Compensation Taskforce, established by Presiding Judge Gerald Fisher in January of 2016, to work on recommendations and guidelines for fair and more uniform compensation for appointees in the Probate Court. The taskforce met 11 times during the reporting period, with some progress made towards tackling a complex and comprehensive list of issues.

The DDS continues to work closely with the Probate Division's GAP. The GAP is a monitoring and educational initiative, and began with students earning their masters of social work appointed as Student Visitors by the Court authorizing them to visit wards and monitor the guardians' roles in their lives, as well as assess other issues faced by the wards. Changes in the law have introduced requirement for periodic reviews by the Court, and the GAP is tasked with conducting those reviews for the Court. In so doing, the Court has hired a number of permanent staff visitors (now known as "case reviewers") who are licensed social workers employed by the Court and overseen by the GAP. However, staffing and budget shortages at the Court are causing some difficulty for the GAP case reviewers to complete their reports and plan the annual Guardianship Conference. The Guardianship Conference has been an important way to educate guardians of all types about recurring issues facing vulnerable people, as well as provide information about resources. It is unclear whether the Court will have the resources to conduct this conference in the upcoming fiscal year. The DDS and the Probate Division are working together to ensure that people served by the DDA are being monitored in the least intrusive manner while still allowing guardianship issues to be brought to the Court as expediently as possible. The DDS OGC provides periodic training for their case reviewers, to help them understand the DDS system and the needs of the people served as well as to lay a foundation for honest communication while they execute their duties. The DDS continues to be pleased with the efforts of this program as it monitors guardians very closely, assists guardians in improving service to their wards, and examines changes in capacity or the continued need for guardianship. This relationship has become more important and more extensive, given the increased monitoring required by the changes in the law this past year. As explained in an earlier section, the increase in monitoring has led to review and reporting on at least 101 people served by the DDS in the last fiscal year.

II. PSYCHOTROPIC MEDICATION TRACKING

In 2013, the DDA implemented a process to track people who take psychotropic medications using the Service Coordination Monitoring Tool, which asks the question, "Has a Physician/Psychiatrist prescribed psychotropic medication?" The Office of Rights and Advocacy also tracks each RCRC review via the RCRC Master Spreadsheet. In FY 2018, each person with a BSP involving prescribed psychotropic medication was monitored at least twice a year and up to eight times a year. The DDA's policy is in the process of being revised, such that the monitoring in FY 2019 will take place four times a year. The status of the psychotropic

medications and BSPs will be reviewed during the ISP process annually or bi-annually, or as otherwise delineated by the RCRC. In addition, each person prescribed psychotropic medications is reviewed monthly by their psychiatrist to ensure the medications are at their lowest effective dose. The DDA continues to refine its process for categorizing all of the discontinued BSPs to ensure they are accurately tracked via the MCIS system.

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